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OLDER WOMEN LIVING WITH HIV/AIDS

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Older Women Living with HIV/ AIDS

Jessica Zager

Department of Human Development and Family Studies

College of Liberal Arts

HONORS THESIS

Thesis Advisor: Thomas Blank, Ph.D.

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Abstract

The purpose of this study is to fill a gap in the literature by investigating how an ignored population of women, women over age 50, copes with HIV/ AIDS. Older women are referred to as "invisible victims" with regard to HIV/AIDS. Previous research on coping with HIV/ AIDS focuses mostly on men. Of the research that does focus on women, older women are often overlooked. Although older women are a minority compared to other HIV-infected populations in the US, they are just as deserving of recognition and care as any other population.

Data was collected through open-ended, in-depth interviews with four women individually. Recruitment of the sample is from several health institutions serving HIV/AIDS populations. The major topics discussed in the interviews include: demographics, what it is like to live with HIV or AIDS, and way of coping with HIV/ AIDS, including social support, religion, and health behaviors. The data analysis process is a qualitative one, with exploration of major themes and presentation of rich descriptions to illustrate those themes.

Results from the data show that in terms of coping, all four participants found it most difficult to cope with a different aspect of living with HIV. Regardless of this finding, participants still employed similar coping strategies. As hypothesized, social support and religious/ spiritual support are important aspects in coping with HIV for all participants. The use of education as a coping mechanism was not an anticipated result. Yet, education was a constant theme, whether it was educating oneself about the disease to better understand it or educating others as to prevent them from contracting HIV. A variety of different positive coping strategies were employed by the participants in coping with their HIV, including altering negative health habits and staying optimistic. Negative coping strategies were also employed, but these seemed

to be discussed less throughout the interviews. Overall, the results of this study demonstrate the resilience of these women in terms of finding ways to live with HIV instead of dying from HIV.

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LITERATURE REVIEW

According to the National Institute on Aging (NIA), an estimated 19 percent of people with HIV/ AIDS in the United States are age 50 or older (2005). In 2005, about 9,893 women were diagnosed with HIV/ AIDS and a total of about 127,150 women were living with HIV/ AIDS (CDC, 2007). Nearly 18 percent of these cases occur in women age 50 and older, with women of color representing the largest number of individuals (Fowler, 2005). Despite such statistics, however, research pertaining to women, especially older women, infected with HIV has been overlooked (Tarakeshwar, Hansen, Kochman, & Sikkema, 2005). Instead, most research related to HIV/ AIDS focuses on samples consisting mostly of men, and older women have been overlooked by physicians and policy makers (Emlet & Farkas, 2001). Not surprisingly, then, older women are referred to as “invisible victims” (Emlet & Farkas 2001, p. 230) with regard to HIV/AIDS.

As a result of improvements in medicine, AIDS has been transformed from an acute illness into a debilitating, but increasingly manageable, chronic illness (Heckman, Kochman, Sikkema, Kalichman, Masten, Bergholte, & Catz, 2001; Jia, Uphold, Wu, Reid, Findley, & Duncan, 2004), and advances in the treatment of HIV means that individuals infected with HIV are living longer (Sikkema, Kalichman, Hoffman, Koob, Kelly, and Heckman, 2000). Despite this transformation, however, many physicians misdiagnose the presence of HIV/AIDS in older women (Emlet & Farkas, 2001). As a result, HIV/AIDS is diagnosed incorrectly as Alzheimer’s disease, cancer, chronic obstructive pulmonary disease, non-AIDS related pneumonia, and Parkinson’s disease -- to name a few (Emlet & Poindexter, 2004).

Similarly, policymakers have focused on HIV-related education and prevention programs at the exclusion of older women, as these types of programs usually are geared towards women

of childbearing age (Emlet & Farkas, 2001). Not surprisingly, due to the lack of interventions directed toward them, older women may lack the knowledge or skills for preventing the contraction of HIV (Emlet & Farkas, 2001). Women's perceptions of their own susceptibility to HIV contribute to the growing population of HIV infected older women. As opposed to their younger counterparts, older women perceive themselves as being at less risk for contracting HIV, even though 65% of women studied engaged in at least one type of 'risky' behavior (e.g., intercourse with a heterosexual or bisexual man, IV drug use, unprotected sexual intercourse) believed to contribute to contracting HIV (Theall, Elifson, Sterk, & Klein, 2003). Additionally, postmenopausal women may believe that they no longer face the risks of unprotected sex (e.g., pregnancy, sexually transmitted diseases), including the risk of contracting HIV (Emlet & Farkas, 2001).

The Experience of HIV/AIDS

Despite the lack of attention afforded by researchers, physicians, and policymakers to this population of women, older women with HIV/ AIDS experience all of the same consequences of the disease that other, more acknowledged populations experience. For individuals with HIV/ AIDS, coping is essential to dealing with all of the emotional, physical, and social consequences associated with the disease. For instance, pain (e.g., headache, joint pain, muscle pain, neuropathy) is a common symptom of HIV/ AIDS (Hart, Gore-Felton, Maldonado, Lagana, Blake-Mortimer, Isreli, Koopman, & Spiegel, 2000) and must be dealt with on a consistent basis. Although the vast majority of individuals with HIV/ AIDS experience pain, the overall degree of pain experienced by older people with HIV may be greater due to their experiencing potentially normative pain associated with aging.

Fatigue is also a common symptom experienced by individuals with HIV/ AIDS,

although fatigue frequently remains unrecognized and hence untreated (Siegel, Brown-Bradley, & Lekas, 2004). HIV-related fatigue may be caused by many different reasons. The source of the fatigue, for instance, could either be a direct result of HIV-infection and its effects on the immune system or a side effect of one of the drugs used to improve quality of life for an individual with HIV (Siegel et al., 2004). For individuals with HIV/ AIDS, it is often difficult for healthcare providers to tell the difference between fatigue caused by a comorbid disorder (e.g., anemia, depression) (Siegel et al., 2004) or fatigue related to the progression of HIV/AIDS.

Individuals with HIV/AIDS also report high levels of emotional distress (Fleishman & Fogel, 1994). High levels of depressive symptoms are common among individuals with HIV (Heckman et al., 2001). In one study, more than 40% of HIV-infected men and women reported statistically significant depressive symptoms (Fleishman & Fogel, 1994). This may be due to the fact that HIV-infected men and women face multiple losses as a result of their illness.

HIV-Related Losses and Bereavement

HIV-related losses are commonly experienced by individuals of all ages living with HIV/ AIDS. Types of HIV-related losses include the loss of employment, functioning, intellect, lifestyle changes, relationships, and sense of control (Sikkema et al., 2000). AIDS-related bereavement, which is bereavement caused by the death of a loved one due to AIDS, is also a common loss experienced by many individuals living with HIV/AIDS (Sikkema et al., 2000).

AIDS-related bereavement negatively impacts both the health and psychological well being of the individual while causing added stress by reminding HIV positive individuals of what they fear will happen to themselves in the future (Sikkema et al., 2000). As many as eighty percent of persons living with HIV/AIDS experience at least one loss due to the death of a close friend or family member with AIDS, and the majority of individuals living with HIV/AIDS has

suffered multiple losses (Sikkema et al., 2000). Men and women who have experienced AIDS-related loss also scored higher on depressive symptoms, general psychiatric symptoms, and traumatic stress related to loss; in turn, these losses lead to increased emotional distress, substance use, and an increased utilization of mental health services (Sikkema et al., 2000). AIDS-related loss often leads to psychological distress such as affective disturbance, demoralization, intrusive thoughts, preoccupation with the deceased person, sleep disruption, substance use, and traumatic stress (Sikkema, Hansen, Meade, Kochman, & Lee, 2005). AIDS-related bereavement has been linked to a greater progression of HIV-symptoms (Sikkema et. al, 2005).

Older Women, HIV/AIDS and Coping Strategies

Given the current and potential circumstances and risks to older women living with HIV/AIDS, research is needed that examines the role of coping in these women's lives. Current research focuses on coping strategies of individuals living with HIV/AIDS with regard to dealing with such consequences. Yet, very little research solely focuses on women.

Coping is defined as "the cognitive and behavior efforts made by a person to alter or manage the problem(s) caused by a specific stressful situation" (Ashton, Vosvick, Chesney, Gore-Felton, Koopman, O'Shea, Maldonado, Bachmann, Israelski, Flamm, & Spiegel 2005, p. 588). Coping may be viewed in terms of negative and positive strategies. For purposes of this study, 'negative coping' is defined as 'an action someone does or an emotion or psychological process they employ that hinders well-being' whereas 'positive coping' is defined as 'an action someone does or an emotion or psychological process they employ that promotes overall well-being'. Coping is essential for individuals with HIV/AIDS, and past coping literature has shown that an individual's adjustment to a stressor is related to the coping mechanisms they choose

(Turner-Cobb, Gore-Felton, Marouf, Koopman, Kim, Israelski, & Spiegel, 2002). To that end, a small amount of research exists that focuses on coping strategies adopted by individuals living with HIV/AIDS. It is important to note not only the kinds of coping mechanisms chosen by individuals with HIV/ AIDS but also the consequences, both positive and negative, generated by these choices.

Negative Coping Strategies

Research demonstrates that individuals coping with HIV/ AIDS often employ negative coping mechanisms, even though negative coping often produces negative psychosocial and physical consequences. In general, research shows that maladaptive ways of coping also are associated with severe reactions of grief for both HIV-positive men and women (Sikkema et al., 2000). Passive coping, which includes avoidance, wishful thinking, and withdrawal (Jia et al., 2004), is related to lower lymphocyte counts in HIV-positive persons (Ashton et al., 2005). Avoidance coping, including denying negative feelings and distracting oneself from feelings, is associated with higher levels of psychological distress, depression, and physical symptoms (Fleishman & Fogel, 1994; Simoni & Ng, 2000). Denial to HIV status is positively associated with pain and is correlated with greater self-reported pain (Hart et al., 2000). Participants who cope with their illness through drugs and alcohol use are less likely to be adherent to medication (Power, Koopman, Volk, Israelski, Stone, Chesney, & Spiegel, 2003). Emotional distress is related to HIV-symptom severity, HIV-related stigma, family rejection, social support, and avoidant coping (Heckman, Anderson, Sikkema, Kochman, Kalichman, & Anderson, 2004).

In one study, the coping strategies of a wide age range of women living with HIV who visited a psychiatric AIDS clinic were examined (Commerford, Gular, Orr, Reznikoff, & O-

Dowd, 1994). The study examined whether differences existed between intravenous drug users and non-intravenous drug users in coping with HIV/ AIDS (Commerford et al., 1994).

Commerford and colleagues (1994) used the Felton Coping Scale (Felton et al., 1984) to measure the following coping mechanisms: cognitive restructuring, emotional expression (i.e. getting angry with others and/or joking about the illness), information seeking, self-blaming denial, threat minimization, and wish-fulfilling fantasy as well as the Anxiety and Depression subscales of the Symptom Checklist 90(R) to assess psychological distress.

Although the researchers found no difference in coping between the two groups, they discovered that negative coping mechanisms of self-blaming denial, wish-fulfilling fantasy, emotional expression, and threat minimization were significantly related to increased feelings of anxiety and depression in both groups of women (Commerford et al., 1994). Of the four coping strategies, self-blaming denial, wish-fulfilling fantasy, and emotional expression were associated with a lack of acceptance of HIV/ AIDS, avoidance, and a general negative affect (Commerford et al., 1994). Women who blamed themselves for their illness had increased levels of psychological distress (Commerford et al., 1994). This correlation between self-blame and psychological distress was also noted in a study by Simoni and Ng (2000), who concluded that blaming oneself for the infection of HIV is associated with higher levels of psychological distress. Previous research has also shown psychological distress is associated with negative coping behaviors including denial, wish-fulfilling fantasy, and emotional venting as well (Fleishman & Fogel, 1994). Commerford and colleagues also found a positive correlation between wish-fulfilling fantasy and negative affect (Commerford et al., 1994); while threat minimization was associated with anxiety and depression in both groups of women (Commerford et al., 1994).

Ashton and colleagues (2005) examined the coping methods of men and women with HIV/ AIDS, but they used a different quantitative measure than the previous study. In this study, the researchers used the Brief COPE as a way of evaluating three maladaptive, or negative, coping strategies (i.e. behavioral disengagement, mental disengagement, and the venting of emotions) and the consequences of using them to cope with HIV/AIDS (Ashton et al., 2005). Results from this study show that a greater rate of progression of HIV is correlated with individuals who use maladaptive or negative coping strategies, as opposed to those who used positive coping strategies (Ashton et al., 2005). Of the three maladaptive coping strategies, venting as a means of dealing with HIV-related issues had the strongest correlation to an increase in HIV-related health symptoms (Ashton et al., 2005). HIV-positive individuals who adopt avoidant, passive, or fatalistic coping strategies are more likely to have a greater progression of HIV disease (Ashton et al., 2005).

Positive Coping Strategies

As opposed to negative coping strategies employed by individuals with HIV/ AIDS, positive coping strategies often result in positive physical and psychosocial benefits. Active coping, which is one form of positive coping, can be defined as a direct and rational approach to dealing with a problem (Jia et al., 2004, p. 595). One study shows that active coping helps promote fewer physical health symptoms, in part due to greater CD4-cell counts and an increase in natural killer cell cytotoxicity in HIV infection found in those who use more active, or positive, coping mechanisms (Ashton et al., 2005). Likewise, individuals with HIV/AIDS who engage in positive coping strategies, such as seeking out information related to their illness or stress management, score higher on QOL measurements (Sikkema et al., 2000).

Positive coping strategies, such as problem focused coping and active behavioral coping,

are significantly related to improvements in quality of life, while negative coping mechanisms such as emotion-focused coping and avoidance coping are related to a decrease in quality of life (Jia et al., 2004). Previous research has shown that positive coping mechanisms such as acceptance, humor, positive reframing, and task focused coping have been related to a better stress response (Turner-Cobb et al., 2002). Even some negative coping strategies, such as avoidance and distraction, have been shown to be beneficial to individuals under considerable stress (Turner-Cobb et al., 2002). Positive reappraisal, goal-directed problem focused coping, spiritual beliefs and practices, and assigning positive meanings to ordinary events have all been associated with positive states of mind (Turner-Cobb et al., 2002).

The Internet as a Means of Positively Coping with HIV/AIDS

Using the Internet as a way to cope with HIV/ AIDS is a positive coping strategy often used by people seeking health information and/or support to help deal with their illness. According to one study, researching for health information online is the third most popular Internet activity (Benotsch, Pope, & Kalichman, 2006; Kalichman, Cherry, Cain, Weinhardt, Benotsch, Pope, & Kalichman, 2006). Past research demonstrates that individuals who cope by actively seeking information are more likely to speak with their doctors, report minor complaints, and have more medical tests performed (Kalichman et al., 2006), which could end up increasing overall longevity. Access to health information online may lead to health benefits for people living with HIV/ AIDS and may empower more people to become engaged in their health care (Kalichman et al., 2006).

Of course, the risk exists in finding misinformation while browsing the Internet. People facing life-threatening and debilitating illnesses (e.g., HIV/ AIDS) may be particularly vulnerable to misinformation on the Internet (Kalichman et al., 2006), and individuals who use

more avoidant coping techniques are more vulnerable to misinformation on the Internet (Kalichman et al., 2006). Likewise, individuals living with HIV/ AIDS must exercise caution when searching the Internet so as to avoid medically unsound information.

Social Support as a Means of Positively Coping with HIV/AIDS

Social support is another positive coping strategy used frequently by individuals living with HIV/AIDS. Within the coping literature, 'social support' used in coping with one's HIV/AIDS status may be defined as "the practical, emotional, and informational help that people receive from friends, family, partners, and/or organizations" (Ashton et al., 2005, p. 588). Research has shown that adaptive coping, which includes the use of social support, can improve the emotional well being of persons with HIV (Heckman et al., 2001). Social support is associated with less mood disturbance (Turner-Cobb et al., 2002) and is negatively correlated to psychological distress (Fleishman & Fogel, 1994). Also, social support was shown to be a mediator of emotional distress caused by stigma and rejection by family members of individuals living with HIV (Heckman et al., 2004). Even the perception that support is available can help to buffer a stressful situation as much as actual support does (Turner-Cobb et al., 2002). Not only does social support improve an individual's psychological well-being, but there is evidence to show that it can lead to fewer physical symptoms (Shippy & Karpiak, 2005), including physical symptoms of HIV infection (Fleishman & Fogel, 1994).

Past research, involving mostly gay HIV-positive men, shows that individuals with good social support networks experienced slower rates of decrease in CD4 T-cell counts, slower progression of HIV to AIDS, and a longer survival rate compared to those individuals who did not have adequate means of social support (Ashton et al., 2005). In one study of HIV-positive male participants, social support was associated with many dimensions of health-related quality

of life, often leading to an increase in health-related quality of life (Jia et al., 2004). Social support positively increased the health-related quality of life of one man living with HIV by lessening another factor related to quality of life - depression (Jia et al., 2004). Likewise, social support for men living with HIV is significantly associated with health-related quality of life, including: fewer disability days and increased social functioning, emotional health, energy, general health perception, overall physical functioning, mental health, and overall quality of life (Jia et al., 2004). Results from this study are supported by the aforementioned study by Ashton and colleagues (2005) which concluded that participants who had high satisfaction in their social support displayed less HIV-related physical symptoms than those who reported to be less satisfied with their social support.

While some studies have shown that social support is related to various aspects of health, one study shows that this may not always be the case for health-related behaviors (Power et al., 2003). In their study of men and women living with HIV, Power et al. (2003) concluded that, unlike perceived support from a partner, perceived social support from friends and family was not a significant indicator of adhering to antiviral treatment. This study, however, was limited in that it did not investigate the effect that social support has on physical or emotional health; instead, the study focused on individuals' actions taken to improve health as a result of the types of social support.

Older Adults, HIV/AIDS and Social Support

Heckman and colleagues (2001) implemented a pilot coping improvement and social support building intervention for older adults living with HIV. The intervention was intended to help the participants to develop adaptive coping resources and access social support in order to facilitate this coping (Heckman et al., 2001). As a result of the intervention, participants reported

significantly less depression, less grief reaction, less psychological distress, and fewer intrusive emotional experiences as a result of learning how to develop social support, express emotions, identify coping difficulties specific to AIDS loss, and set goals (Heckman et al., 2001). After participating in this program, participants reported tendencies to use more positive coping methods, including the utilization of social support from friends (Heckman et al., 2001).

Although it may seem that social support may be the most readily available form of support, this is often not the case. Many older individuals with HIV/AIDS do not possess adequate means of social support (Shippy & Karpiak, 2005), whether in the form of emotional or instrumental types of social support. Diagnosis of AIDS is often linked to a decrease in supportive contacts available, and people diagnosed with AIDS also report receiving less practical and emotional support from their family (Turner-Cobb et al., 2002). Also, older women may see themselves with less support compared to men, since women tend to live longer lives.

Since many individuals with HIV/ AIDS are often disconnected from traditional support networks, the HIV-positive population relies on formal care providers for support (Shippy & Karpiak, 2005). Those who experience the most severe HIV symptoms have less social support, employ more avoidant coping, and experience more emotional distress (Heckman et al., 2004). Approximately 57 percent of older adults with HIV/ AIDS report a lack of emotional support, while 78 percent report a lack of instrumental support (Shippy & Karpiak, 2005). Although women report higher levels of social support as compared to men (Shippy & Karpiak, 2005), 'levels' of social support do not necessarily equate with 'feelings' and 'perceptions' of adequate social support. Furthermore, older adults with HIV/AIDS are more likely than their younger counterparts to live alone (Emlet, 2006; Emlet & Farkas, 2001; Emlet & Poindexter, 2004; Heckman et al., 2001). According to Shippy & Karpiak (2005), 71 percent of older adults with

HIV/AIDS live alone, thereby contributing to diminished social support as well as negative consequences on well being, including increased rates of anxiety, depression, and psychosocial distress. Lack of social support could be problematic because a lack of social support can lead to heightened stigma, feelings of isolation, anxiety, psychosocial distress, and depression (Shippy & Karpiak, 2005).

Religion/ Spirituality as a Means of Positively Coping with HIV/ AIDS

In addition to social support, spirituality, which encompasses one's religious beliefs, has been explored as a positive coping mechanism used by those living with HIV/AIDS. Past research indicates that religious coping is a preferred coping strategy among older adults facing negative life events (Siegel & Schrimshaw, 2002). Specifically, research shows that women infected with HIV commonly use religious activity to cope with their illness (Biggar, Forehand, Devine, Brody, Armisead, Morse & Simon, 1999) and that prayer and rediscovery of the important things in life are two of the most common forms of coping among women with HIV (Simoni & Ng, 2000). Involvement in spiritual activities has been shown not only to improve emotional well-being by decreasing emotional distress and increasing greater optimism, but has been shown to improve physical health by building the immune system (Tarakeshwar et al., 2005).

In one study of African-American women infected with chronic diseases, only half of whom were infected with HIV/ AIDS, a majority placed considerable importance on religious activity as a way of coping with their illness (Biggar et al., 1999). According to the results, 90% of HIV-infected African American women who used religious coping found it helpful (Biggar et al., 1999). In this study, HIV-infected women reported praying more than non-infected women, yet their perception of the effectiveness of prayer as an effective coping mechanism for their

illness was less than that of non-HIV infected women coping with another chronic illness (Biggar et al., 1999). Interestingly, a relationship did not emerge between religious activity and depressive symptoms, as is suggested in other studies (Biggar et al., 1999).

Siegel and Schrimshaw (2002) conducted interviews with HIV-positive African American women over 50 to examine the role of religion as a coping mechanism for their HIV/AIDS. In the interviews, most of the women noted that their personal relationship with God was an emotional crutch in their lives. Due to this relationship with God, many participants found that they felt like they had more control over their situation. A myriad of the benefits of religious coping were revealed through the interviews, include: comforting emotions and feelings, feelings of control, empowerment, and strength, sense of a diminished emotional burden as a result of the illness, reinterpretation of the meaning of the illness and acceptance of the illness, improved health, less fear and uncertainty of death, self-acceptance and reduction in self-blame, social support and a sense of belonging, and spiritual support through a relationship with God.

Tarakeshwar and colleagues (2005) performed factor analyses of the Ways of Coping Questionnaire and the Coping with Illness Scale in order to examine the ways in which adults with HIV cope with this condition. The researchers found that women and ethnic minorities are more likely to use spirituality as a means of coping with an HIV-positive status as compared to White men (Tarakeshwar et al., 2005); however, when grief is added to the equation, men who feel high levels of grief are more apt to use more spiritual coping than White women in the same circumstance (Tarakeshwar et al., 2005). Positive associations exist between religion, psychological adjustment and well being for older men and women (Siegel & Schrimshaw, 2002). The importance of spiritual coping for women has led researchers to hypothesize that a lack of spiritual resources hinders psychological health, leads to psychological distress, and

negatively impacts physical health (Tarakeshwar et al., 2005).

Differences in Coping with HIV/ AIDS Among Different Populations

According to past literature, different populations of people rely on different coping strategies in different ways. Exploring these may help shed light onto how women over 50 cope with HIV/ AIDS as compared to other populations.

Sexual Orientation, Race and Strategies used to Cope with HIV/ AIDS

It seems that patients with HIV who identified themselves as heterosexual were less adherent to treatment than identified gay and bisexual men and women (Power et al., 2003). Coping also seems to differ between different races/ ethnicities. According to this study, white HIV positive participants used more cognitive and behavioral avoidance and emotional suppression to deal with grief reactions, while minorities responded to grief using cognitive and behavioral avoidance (Sikkema et al., 2000). Sikkema and colleagues (2000) found that maladaptive coping differed between white and minority races. African American women are more likely to report feeling responsible for their illness and to keep their emotions from others compared to white women (Simoni & Ng, 2000). White individuals are more likely than African American individuals to seek health information on the Internet (Kalichman et al., 2006). Latina women seem to favor praying and forms of escape such as drug use and daydreaming (Simoni & Ng, 2000). Education and income are negatively correlated to avoidance and denial while positively correlated to active-behavioral coping (Fleishman & Fogel, 1994). Low income, education and employment rate were all inversely related to use of avoidant coping and depressive symptomatology, while positive coping strategies, i.e. seeking information or making plans, are also common (Simoni & Ng, 2000).

Gender and Strategies used to Cope with HIV/ AIDS

Women are more likely than men to use venting as a form of coping (Fleishman & Fogel, 1994). One study reports that having been physically or sexually abused in either childhood or adulthood makes women with HIV/ AIDS more prone to using avoidant coping strategies (Simoni & Ng, 2000). Since fifty percent of the women in the study with HIV/ AIDS reported having been physically or sexually abused in childhood, and 68% in adulthood (Simoni & Ng, 2000) this could be why women use higher levels of avoidance coping compared to men (Tarakeshwar et al., 2005). Few women with HIV/ AIDS acknowledge negative coping mechanisms such as denial and avoidance (Simoni & Ng, 2000).

Men and women both experienced many factors that complicated their ability to cope with HIV/ AIDS, but these factors varied by gender. Middle-aged and older men living with HIV/ AIDS spoke about the difficulties of adhering to medical treatments, negative side effects of medications, changes in physical appearance, and reluctance to disclose their HIV status to others. Older women, on the other hand, spoke about difficulty informing their children of their illness, worried about future well being of their children, and the impact of HIV on their spirituality (which was positive) (Heckman et al., 2001). Research on coping suggests that coping behaviors of middle-class white men are not generalizable to other populations (Fleishman & Fogel, 1994), which is why it is so important that women are treated as a distinct population.

Coping with HIV/ AIDS may be especially hard for older adults because a number of factors, such as few systems of community support, lack of older siblings or parents to care for the person, the stigma of ageism, and many comorbid conditions that accompany older age, can complicate their ability to cope with the consequences of their illness (Heckman et al., 2001).

There is only a limited amount of HIV/ AIDS coping research that includes women in their sample let alone focuses solely on women. Research is needed that examines negative and positive coping mechanisms and strategies employed by the growing number of women who are 50 years old or older and living with HIV/AIDS. Although older women are a minority compared to other HIV- infected populations, they are just as deserving of recognition and care as any other population. Older women with HIV/ AIDS deserve recognition from researchers, doctors, and policy makers. As a result, a more in-depth and richer understanding can be ascertained as to the full range of coping strategies used by older women living with HIV/AIDS. In this manner, gaps in the literature can be filled as more attention is given to this otherwise ‘invisible’ population of women.

METHODS

Participants

Participants for this study consisted of a sample of four HIV-positive women. Since this study was intended to be a preliminary pilot study, it was felt that a small sample of women would be sufficient for an initial examination of the population. Inclusion criteria for this study stated that participants had to be English-speaking women age 50 or older who have been diagnosed with HIV/ AIDS. Women were not considered for this study if they did not meet all of these criteria. Ethnicity and sexual orientation were not relevant to this study. Below is a table outlining some basic information about each of the four participants interviewed.

Participant	Age	Ethnicity	Diagnosis: HIV or AIDS	Approximate Year of Diagnosis	Education
1	51	African American	HIV	1988	Some college
2	50	African American	HIV	1986	Some high school
3	60	African American	HIV	1987	Some high school
4	52	Hispanic	HIV	1993	Elementary school

Procedure

Recruitment

In order to recruit participants, flyers were distributed at community health and service organizations, including: The Gay and Lesbian Health Collective, The Saint Phillip House, Hispanic Health Council, Peter's Retreat, AIDS Project Hartford, and The Windham Regional Community Council. The flyers, which were approved by the University of Connecticut IRB, detailed the study and the contact information for the researchers. Eligibility for participation, which is mentioned above, was also outlined. A thirty-dollar compensation was offered to those who met the eligibility criteria and were willing to partake in the study. It was then up to each woman to contact one of the researchers using the information provided on the flyer if she was willing to participate in the study.

Following contact, the time, day, and place of the interview was completely contingent on the preference of the interviewee. Each interview was estimated to be approximately one hour long and was audio taped only with permission from each participant. A consent form was presented by the interviewer to the participant at the time of the interview. Potential interviewees were assessed by the interviewer to be sure that each woman had the ability to consent. Participants were given as much time as needed to look over the consent form and to ask questions about the study.

Measure

Research for this study was collected through qualitative, open-ended, in-depth interviews with each woman individually. The same interview guide was used for each interview. The interview guide was approved by the IRB prior to recruitment. The interview guide was divided into three sections and had a total of sixteen major questions, with sub-

questions for some of the sixteen. The major topics that were discussed in the interviews include: demographics, what it is like to live with HIV or AIDS, and way of coping with HIV/ AIDS, including social support, religion, and health behaviors. A copy of the interview guide can be found in Appendix 1. Interviewees were told to only answer questions they felt comfortable answering. Listed below for the reader's convenience are two questions written verbatim that were asked in the interview from each major section of the interview guide:

Demographics:

- How old are you?
- How long did you go to school for?

What it is like to live with HIV or AIDS:

- What were your initial feelings or reactions to being HIV-positive?
- How has your lifestyle been affected by having HIV (AIDS)? In other words, what sorts of changes have you made after learning that you have HIV (AIDS)?

Ways of coping with HIV/ AIDS:

- In what ways would you say that the social support of family, friends, and others has helped you to cope with being HIV-positive (or having AIDS)?
- In what ways would you say that religious or spiritual beliefs have helped you to cope with being HIV-positive (or having AIDS)?

Data Analysis

After each interview, audiotapes were coded to ensure the confidentiality of the participants. The student researcher was the interviewer for all four interviews and listened to each participant as she told her story about contracting HIV, what her life has been like since

then, and how she copes with this reality. Audiotapes were then transcribed by the student researcher before they were analyzed for results. After this process, the student researcher read and re-read the transcriptions to come to a greater understanding of what was said by each participants. Connections were then made between the interviews and themes were created that crossed interviews. The results on this comparative analysis can be found in the following chapter.

RESULTS

After conducting and analyzing interviews with four different HIV-positive women over fifty, themes emerged in regard to living and coping with being HIV-positive. Most of the themes that emerged demonstrate a commonality in coping strategies, at least among a majority of the participants. In order to present each theme in a clear and precise manner, I will report on each theme individually. I have broken the interviews into eight themes. These themes include: feelings surrounding diagnosis, disclosure of diagnosis, living with HIV, social support, religion/spirituality, education, positive coping strategies, and negative coping strategies. Each theme is further divided into sub-themes with illustrative quotes for each. As themes are discussed, connections will be drawn between themes when appropriate.

Feelings Surrounding HIV Diagnosis

Initial Reactions to Diagnosis

Initial reactions among participants varied. Two of the women were angered by their diagnosis, while the other two women were more apathetic. One woman in particular experienced a very intense reaction of anger and fear. Yet, her reaction was complicated by the fact that she was pregnant and in jail when she found out she was HIV-positive:

But because I was in jail and pregnant they made me take the test and that's when I legally found out that I was, contracted the virus. They had to do a physical of me to take care of the baby and they came to me and they said, "We have some bad news, we've done testing and we found out that you are HIV positive", and then they sent me back to my cell and then I flipped. I became very angry, violent, mad at myself, beggin' God not to kill the baby, begging God every day every hour every moment that I could think to say, "Please God it's not the baby's fault, please don't let this baby have to come with this disease. I'm sorry, take me." You know bargaining, bargaining really hard with God for that child's healthy life, I begged for his health. (1)

Her reaction seemed to be heightened due to fear of passing her HIV onto her unborn child. Also she seemed to be more concerned for her unborn child than for herself, since she was bargaining for her child's life and not her own. Because of this, it cannot be said for certain if this participant would have had the same experience if she had not been pregnant upon diagnosis. She also goes on to describe how enraged and animal-like she became as a result of being diagnosed with HIV:

When I went through all that anger and stuff I was so terribly angry that I ended up in solitary confinement, I was like an animal, nobody could come near me, I was so violent and spewing like I was a demon possessed. You know, I screamed 'till frothy spit came out my mouth. I was like a real monster. (1)

From the content of the interviews, it seems that no other woman experienced such a strong initial reaction. One other participant reported she was angry when she first found out she was HIV-positive, but did not go into much detail. These were the only two women that admitted to feeling anger and upset after hearing of their diagnosis. This woman was upset because she had learned that a man she was having a sexual relationship with at the time was an IV drug user and was HIV-positive but had not disclosed his diagnosis to her until afterwards:

I was upset 'cause I caught it from a guy using needles. That's how I got it, through him. I didn't know he had it. He told me to go to the doctor 'cause he wasn't sure and I went and that's when they told me. [I was] angry. (3)

This participant's initial reaction was complicated by the circumstances of her diagnosis. In this situation, the participant's reaction seemed to be influenced by the fact that she had unknowingly contracted HIV from someone else. The lack of control over the situation may have contributed to her initial reaction of anger.

Unlike the first two participants mentioned, the other two participants had very different reactions upon being diagnosed with HIV. Both of them disclosed that they were not surprised to hear their diagnosis due to the IV drug style they were living at the time. One woman even

admitted to sharing needles with individuals she knew had AIDS without being concerned as to whether or not she would contract the virus:

My friends that had it, I watched a lot of them pass away and I shared needles with them, you know, I really didn't care. I really didn't know much about it...I already probably knew [I was HIV positive]. I had an idea because they had it and that's how you catch it. (2)

When questioned about feeling any negative feelings after being diagnosed, she stated that she did not think she had any and if she did then she was not aware of them. It seems that her lack of knowledge about HIV/ AIDS led her to be careless while sharing needles. Another participant also had a similar subdued reaction to her diagnosis. Yet, unlike the previous participant, this woman alluded to feeling some fear for how her life was going to change due to the diagnosis:

I wasn't surprised because of the lifestyle I was living. So it was something to be expected...I think after a couple of days I felt, like, paranoid, like "Well, what I'm gonna do? What gonna be my life now when I get out of [jail]?" But then I learn how to live. (4)

There are many confounded factors that go into what shapes someone's reaction to being diagnosed with HIV. It cannot be concluded from what they said in this interview why some of the participants responded in anger and others apathy.

Acceptance of Diagnosis

Despite the varied initial reactions, all of the participants have come to accept having been diagnosed HIV-positive. For the two women that had the initial reactions of anger and fear, it took them a few years before they accepted their diagnosis. For one of these women, her acceptance came as passing time subdued her fears of death and isolation:

I accepted it when I found out that it had been 20 years I had had it and I was still alive. And I accepted it when I found out that I lived a normal life just like everybody else. There was no mark on my head or the back of my shirt that said I got [HIV]. (1)

The longer she lived with her HIV staying stagnant and not progressing into AIDS, the more accepting she became because she felt like it could not hurt her. Another participant also came to accept her diagnosis after relinquishing her sense of control of the situation over time. It took her about ten years after she was diagnosed to come to this conclusion:

I know there wasn't nothin' I could do about it. So I just have to, have to deal with it goin' on with my life – that'll make it better. I realized a lot of things about it. (3)

Both of these participants were not able to accept their diagnosis until years afterwards. This could possibly be tied to the fact that they both experienced strong initial reactions to their diagnosis, but this is not certain.

The two participants that expressed apathy towards their diagnosis both stated that they had accepted the diagnosis as soon as it was given to them. One woman stated:

“When I first found out [about the diagnosis] I took it in, in one ear and I just kept it inside. ‘Cause the more you worry about it the worse it gets.” (2)

This was the same woman that knowingly shared needles with HIV-positive individuals and did not care about contracting HIV. This may be why she accepted her diagnosis so readily. The other participant also accepted her diagnosis immediately:

“I think [I accepted the diagnosis] the same time when they gave it to me.” (4)

It is possible that both of these women were able to accept their diagnosis right away due to the fact that they knew they were engaging in behaviors that would cause them to become infected.

Current Feelings of Diagnosis—Primarily Positive

All four participants experienced a shift in how they feel about their diagnosis from the time of diagnosis up to now. Three of the four participants reported a positive conceptualization of their diagnosis at this point in time. One woman reported feeling proud of herself, despite

being HIV-positive. Her pride comes from feeling strong enough to have fought the HIV for over 20 years:

Three hundred and sixty whatever plus if you go again around I changed all, totally... I feel proud of myself, look at me. Yeah I got it but it's not hurting me. Yeah it's in there but it's not a problem yet. (1)

She is proud of herself now because of how long she has been able to live without the HIV progressing. After twenty years of being HIV-positive, she feels as if she can “beat” the disease. Another woman reported that the fear she had once felt had left her after she figured out how to cope with HIV:

I learned to deal with it. I got it so I have to deal with it. Um, fear, fear no more 'cause now I understand it and I'm dealin' with it, and so far I've been doin' pretty good. (3)

Another participant answered that having HIV did not make her feel left out or like an outsider. She seems to have a good self-image despite having HIV:

I really don't feel left out. I don't feel that I'm sorry, yeah I'm sorry because I got it, but I don't feel like sorry for myself because I'm not the only one. (4)

One of the four participants reported experiencing more negative feelings since the time of her diagnosis. This is interesting because she is also one of the participants who reported feeling apathetic at the time of her diagnosis. After recently being told by her doctor that her HIV was progressing, she has been feeling more negative emotions.

Now I'm starting to worry more. Because they said I'm not undetectable anymore... Yeah, it is getting worse. (2)

She was the only participant that admitted to feeling an increase in negative feelings since the time of her diagnosis. She is also the only one who spoke about knowing that the progression of the HIV was getting worse. It is unknown if other participants would have a different conceptualization now if they were told that the status of their HIV progression was changing.

Self-Image as a Result of the Diagnosis

Becoming HIV-positive has impacted the way most of the participants view themselves. Most spoke about how having HIV has impacted their self-images. One woman spoke about the impact HIV had on her self-identity and how the HIV has become an inextricable part of herself:

It's something that you have that's inside yourself. Sometimes you want to talk about it and sometimes you don't - but it's always there. And you think it and you feel it within your heart and you feel it within your soul that it's you that have it.
(2)

This view that HIV is not just something that you contract, but it is something that you have, something that becomes part of who you are, seems to have a permanent effect on the mindset of those with HIV. One woman used negative adjectives while describing herself compared to her boyfriend who does not have HIV. She talks about how she is now tainted, both in her body and in her relationships, due to the HIV:

I carry his paper that say he clean, you know, I keep those papers for him just in case anybody want to know – he's clean. You know, so I'm the devil, not him. You can't give blood if you want to 'cause your blood's tainted. I'm tainted. Relationships, oh, when do I be honest? Can I be honest or not? Should I be honest or not?... and so on. Relationships, you feel tainted there – if I tell them [about being HIV-positive]. (1)

By referring to herself as “the devil” and “tainted” it seems that this participant has adopted a negative view of herself as an HIV-positive individual. This same participant also reported that having HIV makes her feel isolated and like an outsider due to the way other people treat her once they find out she is HIV-positive:

And people treating you different. The doctors treating you different. It's like once they knew you had the virus you knew the room would fill up with interns and you went to the doctor 'cause one thing but then it ended up all throughout the time the main interest people had in me was just that I had contracted the virus and they wanted to do a studies and all that and I was embarrassed and it was just embarrassin' and it was weird. Because they forgot the initial problem I came for – like with my bronchitis or my asthma – 'cause once they find out I had the virus it was like everybody, people would just come in, there would be students and

pre-school doctors and people doin' their, um, whatever's. And so they said do you mind if they come in and I said, "No". But I should have never said that, it was like having reporters around me because everybody be asking me questions and it was embarrassin'. (1)

Yet, not all of the participants develop a negative view of themselves as a result of their diagnosis. As previously quoted, one participant reported having a positive self-image despite her diagnosis:

I really don't feel left out. I don't feel that I'm sorry, yeah I'm sorry because I got it but I don't feel like sorry for myself because I'm not the only one. (4)

Instead of viewing her diagnosis as something that had separated her from others and had made her feel like an outsider, this participant felt comfortable with her self-identity as a woman diagnosed with HIV because she knew that others share this diagnosis as well.

Disclosure of Diagnosis

Feelings of disclosure among participants were varied. While some participants were open to disclose to nearly anyone, others were more hesitant. Feelings surrounding disclosure varied among participants depending on whom they were disclosing to, personal differences in feelings of disclosure, and personal reasons for wanting to disclose.

Disclosing to Non-Family

The two participants who had little initial reactions to their diagnosis and accepted their diagnosis right away are also very open about informing non-family of their diagnosis. One of these women tells how she is not afraid to tell others she is HIV-positive:

Well, I don't just bring it up. But like say, for instance, I'm having a conversation, I'm saying like, "Well you think you're bad, right now I've been livin' with HIV for years." And I thank God for that and you know I just let 'em [know of the diagnosis]. I'm not afraid to let anyone know. (2)

Likewise, the other participant that accepted her diagnosis right away is not ashamed of letting anyone know about having HIV. In fact, she offers her time to talk with strangers about it:

And I don't have fears when talking about it. I was doing outreach... I used to do a lot of speeches with kids at school and all that stuff, it helps me a lot. (4)

Not only is she not ashamed of disclosing to non-family, she feels it also helps her to cope. Yet, just because she is open to telling anyone of her diagnosis does not mean she does not recognize or utilize her right to be selective:

The people that I meet, either I tell them or I don't – it's up to me. (4)

Yet, not all of the participants are this open to share their diagnosis. One woman seems much more guarded and much less likely to disclose her diagnosis, especially to those she feels will use it against her:

It depends, I get a feelin'. I always get a feelin' of who's who. Some of the doctors in the beginnin' when you first got it back in those days the doctors said be careful who you disclose this to because, um, people might treat you different at your job, blah blah blah, shun you. You kept it personal, you wasn't suppose to go out only if a person was at risk did you disclose it. To this day with some doctors I don't say nothing because it's in my records I don't have to say shit 'cause you see it. You know, 'cause how do I know what they got listening, voice you know, I don't know. I don't trust some people at all when it come to my virus. I protect it at time you know 'cause some people just want to know so they can exploit you or not give you insurance policy and stuff like that. (1)

She seems to be much more fearful of becoming vulnerable to those she discloses to. She feels that some people will use her diagnosis against her instead of offering support. Also, this participant recounts how she was hesitant to tell her prostitution clients that she was HIV positive because that meant that she could not make money to buy drugs:

And so I said, to these guys when I would have to prostitute to get my money for the drugs, they said, "You straight, right?"

And I said, "What you mean?"

"You clean, you ain't got no diseases, right?"

Now I asked you, an addict who needs a drug has a choice of tellin' a man "Yes I have it", and them sayin' "Well you've got to get out of my car", or "No I'm straight." 'Cause it's so simple to just say "Yea", you know. You don't even got to speak to acknowledge it, you could just nod...that's how it's spreadin' 'cause people lie. (1)

Any time she felt like she would be treated differently she kept her diagnosis to herself, even if this meant putting others at risk of contracting HIV. It seems that in some cases, disclosure to non-family does not occur if the HIV-positive individual knows that disclosure will mean they cannot get the drugs or resources that they need, even if this puts others at risk.

Disclosing to Family

As with disclosure to non-family, feelings about disclosing to family were varied. One participant did not hesitate to tell everyone in her family about being diagnosed with HIV:

Everybody in my family knows. The more important thing in my life is my son and my family. Those are the important parts of my life. All my nieces know what I'm having, they know what I have and they love me just the way I am. So, like I said, it won't bother me if someone out there say whatever or do whatever, you know, it would bother me from my family but I know they're not gonna do it. (4)

She was willing to tell her whole family because she was confident that her family would still love her and care about her. She was the only participant that was this secure with her family to be open and honest with everyone without insecurity. Another participant was open with her family, but it took her a while to build up the courage to disclose:

It took me a little while, but I finally end up telling my mother and my sister but they had already knowed and I didn't tell them. (3)

One woman felt that keeping it in the family would not be as embarrassing as telling non-family:

So to save myself real embarrassment I kept [the diagnosis] in the family with the two people closest to me, which was my mother and my sister who raised Kyle.
(1)

Yet, since she was in prison and pregnant when she found out she was HIV-positive, she was forced to tell people about her diagnosis, especially the family members that would be taking

care of her child. It is unknown whether or not she would have told her family if she did not have to, since she has decided not to tell her sons:

I never tell them (my sons) about me because the day that they get the courage to ask me is the day that they get to know. Not unless I'm on my way out you see.
(1)

Feelings about Disclosing

Among participants, feelings about disclosing their HIV status differ. Two participants view their ability to disclose to others as a gift from God:

And I thank God for that and you know I just let 'em [know of the diagnosis]. I'm not afraid to let anyone know. Because I'm me. If you can't accept me for me than you just don't have to be here. (2)

After being questioned about why she finds no difficulty in disclosing, the other woman stated:

I think that was a gift from God I think. 'Cause, I mean I know about people that do God and never talk about it and stuff like that but that's their personal life, you know. I cannot judge 'em for what they do, it's just somethin' that was given to me so, I want them to do it but there's nothin' I can do about it. (4)

The view of the woman who had trouble disclosing to both family and non-family is very different. She sees disclosure as something that can hurt an HIV-positive individual. In her opinion, someone who is HIV-positive has a great potential to be hurt if they choose to disclose their diagnosis:

It's the biggest risk you can take is disclosure. Where it hurts you on one end where it may help the doctor, it might hurt you because now you're supposed and as I said when I met you when you give out information people can do what they want with it. So whereas [you] might do positive things, [your advisor], whatever his name, the other guy, you know your supervisor, he might do it another way. And where you do it caringly he does it bluntly, business, no feelings, no care just he got a focus point and that's what he's gonna do no matter who he has to step on to get there. You know what I mean. So that's how you lose, with the risk you take with disclosure. That's the biggest thing I can think of how you hurt yourself – disclosure because at that moment you either make it or break it, well it's good or bad, if you're gonna be hurt or not. So you have to really, really be careful who you disclose yourself to. Insurance companies, you know some of them almost make you have to lie because, my – leaving my son some money to have to help

with my funeral so he won't have no problems, you know or burdens when I die, or my mother or my family, well some insurance won't take me on for life insurance just because they know that it's a fact that I'm dying within the next 20 years, they think. (1)

This participant clearly feels that disclosing one's HIV-positive status invites the potential of being taken advantage of by many different people. This is why she is not as open with her diagnosis as the other participants, for the other participants did not seem to feel the potential risks of disclosure.

Reasons for Disclosure

Throughout interviews with various participants, different reasons or motivations for wanting to disclose their diagnosis were discussed. One participant said that she disclosed her diagnosis to her family because she needed the support of her family to cope with being HIV-positive:

[Why did you choose them to tell?]
Because I couldn't do it alone. I needed some support, some love. (3)

This same idea came up in another interview as well. Another participant spoke of how she had a hard time coping with her diagnosis since she felt like she could not disclose to those around her and therefore did not have their support:

And it was because at that time I couldn't tell people and if I had said something to anybody in jail everybody would have started talking about me, "you know she got the thing"... So I had to hold all this pain in and it was consuming me and I let it come out as anger. (1)

Acceptance was another reason for choosing to disclose. One woman reported that she chose to disclose to others because she wants to be accepted the way she is:

So that's why I thank God that God gave me that gift of being open-minded and say, ever since 1993 I went to a lot of treatment center and lots of programs and stuff like that and everywhere I go I talk honest about everything what's goin' on in my life 'cause I want people to love me for who I am. (4)

It is apparent that there is considerable diversity in feelings surrounding disclosure, including feelings of whom to disclose to. For some of the participants, disclosure is a way of coping by gaining the love, acceptance, and support of family and strangers. For others, disclosure is something that is not a useful coping mechanism and instead is something to be cautious of and to fear.

Living with HIV

Hardest Aspect of living with HIV

When questioned about what they felt to be the hardest aspect of living with HIV, each participant responded differently. One woman felt that disclosing her diagnosis to others, particularly family, is the hardest aspect to cope with in terms of being HIV-positive:

The hardest part is being honest with my family... and my children.

[Why?]

Judgmental and rejection for the fact of isolating me or rejecting me or just choosing to use it as gossip to run around with family friends and just tell because of sibling rivalry. You don't get along with every sister and every brother. (1)

Another participant answered that taking the medicine was the hardest part of being HIV-positive:

Taking the medicine. I worry a lot and my body has changed. I'm getting older and older, so that's natural probably to be. I need to do a lot more things like take my medication, you know, stay on track with that. I never really liked to take pills. I have to. Now that I know it's starting to get serious I gotta take it. So it's not like before. (2)

One woman reported that her mood-swings were the hardest part to cope with after being diagnosed as HIV-positive:

The moods, the changin' of the moods. You might feel good one day and the next day you might not feel so good. You experience the way you accept it. Like some days you can feel real lousy, like I don't want to be bothered, and some days I have great days. But I always pray in the morning then I know, I know that day is good for me. (3)

One of the participants clearly stated that she felt there was nothing difficult to cope with in terms of having HIV:

There's nothing. Like I said, I'm so open-minded. (4)

Even though every participant found a different aspect of coping with HIV to be difficult, coping strategies among the participants did not vary tremendously. So, even though each is struggling to cope in a different way, the modes in which they combat these obstacles are very similar.

Age and HIV

Only one woman spoke about what it is like to be an older woman living with HIV/AIDS. She gives great insight into the difficulties of being an older woman going through the natural aging process on top of living with HIV:

Now this is what 50 do for you. Now you shoulda asked me that too, what do 50 do for you? Ask the next person what do 50 do for you. See it's already fucked up being 50 without the virus. But to be 50 with the virus, you really get crazy, girl. 'Cause your goin' through menopause, which is normal and a woman is like a crazy person when they go through menopause. You argue, you act like you crazy, you cry about nothing, you mood swing like crazy. That's without the [HIV]. Then you put that motherfucker on top of it and boy you might not fly. Shit. And that's how you get when you get older. It make you think you're getting Alzheimer's. (1)

She also recognized that it was important for her to know the difference between the normal aging and HIV-related symptoms:

There are certain bodily functions that changes just because of age. Period. So it's not always HIV related. So you have to learn how to decipher, what's life?, normal life health?, your history? (1)

When questioned about their thought on whether it is more difficult for a younger woman or older woman to be diagnosed HIV-positive, three of the four participants responded that they thought that contracting HIV at a younger age is more difficult than contracting it at an older age. One woman said if she had contracted it when she was older she would have been respected more:

So, if I was younger or older when I got it - I think maybe older I would have got more respect. (1)

One participant said she thought being diagnosed at a younger age would have been harder since not many people knew about HIV/ AIDS then:

Because they didn't talk about HIV and AIDS back then, it was always a hush-hush and you were scared to let people know because of the reactions.
[So, you think it would have been a worse reaction if you were younger?]
I think so. (3)

Another woman also reported that she thought she would have had a harder time if she were diagnosed when she was younger because her family would have been less accepting of it:

If I was younger. 'Cause I come from a big family, eight sisters, and I'm the only one that's messed up in the house. I think that if I would have say-ed [sic] it at a younger they would have never accepted it. (4)

Social Support

Social support was a common mechanism used by all participants to cope with being HIV-positive, regardless of how many family or friend they had accessible. Only one participant had the support of a romantic partner. All participants lived alone and all but one, the one who is in an intimate relationship, prefer to live alone. Yet, each woman found some source of social support to help her to cope with having HIV. Family was a valuable source of support for most participants. All of the participants had children, but many were not close with their children because their children had been taken from them due to drug use and alternating between living on the street and doing time in prison. All but one felt that their family provided important social support.

Emotional Support

Emotional support refers to “the things that people do that make us feel loved and cared for, that bolster our sense of self-worth” (Seeman, 1998). Each participant received some form

of emotional support from others in her life. One participant spoke about how her mother is the main source of emotional support in her life and the importance of that support:

So my mother supports me. That's the one I can talk to about anything and she don't judge me and she always encourages me. (1)

She also spoke about how valuable it is to be part of an organization that supports people with HIV/ AIDS. To have a place where she can go and receive emotional support from non-judgmental people seems to be a really important source of emotional support:

Anything negative that come you got to push it away, so we need people to call us and say, "What are you doing? Is you in the bed? Nope, get up! We have this goin' on." And that's what makes me come here because I know I got a safe place to go to and with professional people who look at me with respect and treat me normal. Even despite all my disease and germs they still sit across the desk and choose to conversate with me. Makes me feel equal. So instead of wasting my day laying in bed and thinkin' about everything that's wrong I can get up and come here at ten o'clock and talk to somebody. And that's therapeutic in itself you know. So that's what we need more of. (1)

This participant also talks about how she feels emotional support can be more valuable than instrumental support, which is discussed in the following section:

So people need support systems, 'cause, you know it's not always money that we need. What we really need is to know that we're no different than others and that people care, you know, and we want, you know there's not a person that has the virus or AIDS that don't want affection. You know, I'm not askin' people to come everybody hug us all the time but a hug would mean a lot and a good ear helps. You know. (1)

Another participant, who does not have many friends or family around, receives emotional support from younger generations:

The most that makes me so happy and makes me get out everything when I'm angry when I'm upset when I'm stressed when I'm depressed is when those kids come to my door. "Auntie I just came to see what you were doin' " "Hi Auntie I really miss you" "Auntie can I come in" stuff like that and it makes me think about my kids too and I just thank God for them. Because the people who I expect to come by don't. [Like] family, people you think are your friends that aren't, people you thought that cared that don't, you know. (2)

Another women spoke about how talking with her family helps her to cope and reduce negative feelings related to having HIV. Similar to the first participant mentioned, another source of emotional support for this participant came from the organization she is closely associated to and the services they provide:

Yea, [talking to my family] helped ‘cause they were accepting and we could, you know, talk about it. I go to groups, support groups, they’re supportive in here, and my family and me dealin’ with it by myself sometimes when I think about it.
[How does it help you?]
Oh, everybody’s like a family in here and you can talk to the staff and you can do things, different things that come up. (3)

One participant also spoke of the importance of her family’s emotional support in her coping with HIV. For this participant, just knowing that her family loves her despite having HIV provides her with emotional support to cope with the disease:

I feel more happier now because of my family, even though they don’t visit me as much as I want, but they love me unconditionally. I can see the love they got for me. (4)

She later goes on to explain how without feeling the love and support from her family, without the emotional support, she would not have the desire to live:

Because I think that living with this disease, I have seen it, it’s very painful and very stressful – a lot of things, and knowing that your family knows that you have it and support you less, that would be a killer to me. I would go in the street and get high and say to hell with it. Die, I mean, just use drugs until I die. So today I don’t think like that. I want to live for tomorrow. (4)

Instrumental Support

Instrumental support refers to “the various types of tangible help that others may provide” (Seeman, 1998). Basically, it is support that fulfills needs other than emotional needs.

One woman spoke of how one of her sons provides emotional support by checking up on her:

My oldest son he comes periodically to check out how much food I have in the cabinets and to see if [my boyfriend] is helping me and he checks on me to make sure I’m okay. (1)

In talking about support in her life, this participant also spoke about the importance of instrumental support in the life of someone with HIV/ AIDS:

We need more of free people that do massages to devote their time. People who cut hair to, um, donate their time to give some of us hair cuts or makeovers because in our depression and state in this disease we think that we don't look good we feel ugly. So that works because when I was in New London, it was called Alliance for the Living, and it's like this base that modeled this whatever, and that's what they did. They used to have every 90 days they'd have hairdressers devote say 6 hrs in their day to come to the center and get hair cuts. And they's get times every week they gave massages, there were certain masseuses that would you know devote their time to charity. And they come there and give people – that's therapeutic. Massage has the value of the same thing of sittin' down for an hour with a psychiatrist they say. (1)

Only one other participant mentioned receiving instrumental support from social support, but there were not specific questions in the interview guide asking about types of support social support provides. She talks about the security she feels in knowing that her family provides this support:

Knowing that if I get sick I got my family there. Knowing that if I was to leave this apartment right now and pick everything, take everything with me I could go home. I could go to any of my sisters' house, I could go to my mother's house. That helps me a lot. I couldn't say that before. (4)

Informational Support

Informational support, which is sometimes considered instrumental support, refers to “the help that others may offer through the provision of information” (Seeman, 1998). Two women who participated in the study reported that they received spiritual encouragement via informational support from their mothers. One woman spoke of how her mother gave her information about God and his all-knowing and healing role in her daughter's HIV status:

But my mother- we talk about good health and we talk about goin' to the doctors. My mother participates in my health issues, you know. As we know, she tell, just as my mother always say she said “God made the doctor, God is the doctor and without God the doctor can't do nothing” so that she said “Doctors learn from a

book just like you and I and the same way the doctors learn you can pick up a book and learn too” and she says that um, “Sometimes even doctors don’t know.” You know, that “They get all their information from you about you. So if you don’t tell them then they don’t know certain things. So communicate with the doctor.” She said, write down if I have questions, write em down and when I go see ‘em the next time bring that and say this is what I thought about when I was away and she, she’s excellent. My mother is a wealth of wisdom and honesty and study and she believes in workin’ hard. (1)

Another participant also relied on her mother for informational support by advising her to pray to receive help from God:

Just my mom. She passed away, on umm September 22nd. I talked to her all the time. [She helped me] by giving me the faith. [She told me to] keep praying. Ask God to just try to help me. (2)

Negative Effects of Social Support

Only one participant stated that social support has “worked against” her in her struggle to cope with HIV. This same participant spoke of how her family is not around or accessible to her, especially since her mother, her only source of social support in her family, had just passed away. She explains why she feels her family’s support has “worked against” her:

Yeah, oh yea. They wouldn’t have an idea. They think it’s like luddy-doddy. I guess they don’t see my expressions, you know. It’s like we’re distance, very distant.
[Why?]
I guess because I still get high every now and then. They were money hungry and they were into themselves and when I had something they were here and when I didn’t they weren’t.
So is that why you are distant?
That and I’m very angry with them. (crying) (2)

It seems that she feels social support from her family has worked against her because they have not made themselves accessible sources of support.

Religion/ Spirituality

Along with social support, religious/ spiritual support was employed by all four participants as a coping strategy. This theme is broken down into three sub-sections. These sub-

sections outline specific religious/ spiritual acts and beliefs that aid in coping with being HIV-positive.

Prayer

All participants spoke about using prayer as a way of receiving support from a higher spiritual power referred to by all participants as “God”. One woman says that she copes by praying continuously:

I pray every moment. I talk to him, I talk to God like I’m talkin’ to you now. (2)

She goes on to explain that she prays to God to give her the strength to accept what will come in the future once she has contracted AIDS. She also shows her loyalty to God, which may come from the belief that He has the ability to help her cope with being HIV-positive:

I say, you know, “Lord just let me be ready when it’s my time.” No matter what it’s from or whatever I just hope that while I’m here I can do the best that I can to fulfill the needs that he wants. (2)

Another participant prays to thank God for giving her one more day to live. She does not ask for his help, but just knowing he has given her another day helps her to cope:

Every morning I wake up and thinking God gave me another day. It help me through that day, through the struggles and through everything... And I pray for everything that I got and I thank God for that. (4)

One woman reported that she prays to God both for consultation and to give thanks and praise to him to aid her in decision-making and to give thanks for all he has given to her:

I consult my higher, well God, my spiritual being superior. I consult him on a daily basis before I make major decisions and just thanking him for what I choose to call a healthy life and for saving me for the grace and mercy that I believe my higher power and spiritual superior has given me. (1)

Only one participant prayed specifically to receive relief from her fears of having HIV:

Sometimes I used to be scared and now I pray to God and I always ask him and he helps me a lot, by praying. Every morning I get up and every time I go to bed [I pray]. (3)

It seems that there is a two-fold purpose in praying for these participants. Prayer is a way to ask God for help, and they attempt to cope with their HIV and it is a mode of expressing gratitude to God for this help.

Faith

Having faith in God was a common theme discussed by three of the four participants during interviews. One participant spoke about the faith she has and how it has helped her to cope with being HIV-positive:

Well you walk by faith and you see, it gets validated by life. You see your own personal relationship - see, 'cause its different for everybody. It's different and that's why people get afraid of believing in something, havin' faith in a God you can't see. So it's touchy but I read and I try to apply and then I see and I found it to be true - that it does work...So, faith in something you don't see. That helps me, so much 'cause this disease is scary. (1)

As another participant who uses her faith as a way of coping with HIV simply stated:

It helped me a lot to have faith. (4)

One woman, in being asked what can “hurt” you or someone else trying to cope with HIV, stated that not having faith and hope can make it difficult for an HIV-positive person to cope:

If their hopes are gone. If you lose faith and hope. (2)

Although no participant went into much detail about how her faith has helped her cope with having HIV, it is apparent that having faith does help. It is also interesting that one of these women did not practice a specific religion before she was diagnosed with HIV. After she was diagnosed, she began to have faith in God and pray to him, although she continued to not practice a specific religion.

God's Divine Power in Coping with HIV

Another common theme that came up in regard to religious/ spiritual coping is the belief that God is more powerful than any person or doctor; the belief that he is the only one who can help these women in their struggle with HIV. One participant says that she knows God is the only one who can help her cope with her HIV:

I tellin' myself God will take care of me. 'Cause I know he the only one that can help. Religious is good, it makes you feel good. By being into that, that's enough, that's enough for you. The religion and the prayin' to God. 'Cause I know he the only man that can help you go through it. If anybody can do it he can. (3)

Another participant shared her belief that God is watching over her and has forgiven her for the drug use and other mistakes she has made in her life:

And I know that it's God who's watching over me, over all the things and he forgive me for all the things I did. (4)

One woman told the interviewer how she believes that God is more powerful than any doctor and protects her from potential harm from her HIV:

I really believe there is someone greater than any doctor, than anyone who has kept me from being dead...I'm keepin' it at bay and it's not destroying me and I attribute that to a higher power, some spiritual realm that I can't explain. (1)

This participant relies on God for all decisions she makes because of her belief that God is above all else. It helps her to cope with her HIV status to know that she has the help of God in her life and that his help is all she needs:

I told God, this is how I work it out. Every time I got a major decision, there's a bible verse that says "I will look to the hills from whence cometh my help, my help comes from the Lord who made heaven and earth," so that's my consultation. That's telling me don't look around at offices and businesses and doctors and stuff. Look to the hills, look to the heavens and the skies and who made all of this and then ask it the question that no one else can answer. You know only the person that can see in the future and knows me totally can answer some questions and that's who I call my higher power and I choose to call him Jesus Christ and God. And that's, when I have great decisions, that's who I trust to point me in the direction. And that's what I do because he promised that if I do these thing that he will guide me, promises a whole lot of stuff too. But if I take, footwork you know, if I take the first steps he'll make the rest. He'll make sure, if

you do something for yourself, he'll back you up. You know, if you just do all you can and then just sit back and have faith, he'll fit it. And I've found that to be true. (1)

This belief that God is omnipotent, or all powerful, seems to help these participants by instilling a sense of security in knowing that someone or something this powerful is looking after oneself.

Education

The use of education as a coping strategy was discussed in all four interviews. Two variations of education as a coping mechanism emerged. The first was to educate themselves about HIV or how to live with their HIV. The second form of educational coping involved teaching others about HIV and how to keep from contracting it. Participants employed either one or both forms of education.

Educating Yourself

Three of the four participants reported that educating themselves about HIV/ AIDS and how to live with the disease has aided their coping process. One woman spoke about how educating herself about different ways to combat the HIV has helped her to cope:

I started educating myself about nutrition, anything I could do to help fight it, anything I could learn about it I absorbed like a sponge. And once I understood it and the next thing I know I had lived over 5 years and the next thing I was 10 years and the next thing I was over 15 and now I'm over 20 years. It's like, now I know it can't hurt me. So I educate myself. Educatin' yourself and livin' a positive life and eatin' right and restin' – all of the things that they taught you anyway. If you just do that you got a chance. (1)

She also spoke about how she would use the Internet to educate herself about having HIV/ AIDS:

Me, myself, I pay attention and I go online, checkin' studies, checkin' blah blah, any information on what medications. And I'm finally learnin'. I'm learnin' a lot from goin' online and learnin' about case studies. (1)

She was the only woman to bring up using the Internet to find information about HIV/AIDS.

Another woman told of how she educates herself about HIV using any information that is available to her. For this woman, learning about HIV helps her to combat the negative emotions she experiences:

‘Cause I know more about [HIV], it helps to relieve the tension and stuff. Now I know the situation that I’m in and I know it’s very powerful and as long as you take your meds and stuff you’ll be very fine. I learned about it by readin’ books, pamphlets, and stuff like that. Everywhere I see ‘em, wherever I’m at I pick up one and look at it and read it. (3)

Another participant spoke of how she educates herself on how to stay healthy by learning how to stay away from drugs, which is how she contracted HIV. She also has taught herself how to utilize social support to cope:

[I cope] by learning how to stay clean. Went to meetings, talking to people, and learning from them. I learn how to talk to people and tell people my life, what was going on with [me]. (4)

Educating Others

Along with educating oneself about what HIV is and how to cope with it, it seems that helping to educate others about HIV helps HIV-positive women with their own coping. Three of the four participants reported that educating others has helped in their own coping process with HIV. In being asked about coping strategies, one woman mentioned how she copes by talking to others about her experience with HIV and educating them on what it is and ways of preventing it:

A lot of volunteers come here and we talk to them and tell them our stories. Even kids that come here. We had a group of kids to come here and we told our stories, tell them to let them know, use safe sex. (3)

Specifically, she spoke to others about the importance of practicing safe sex, since she contracted HIV from not having safe sex with an HIV positive man. It seems that the women who taught others about HIV and how to prevent oneself from contracting it focused on helping others

prevent contracting HIV the way they did. For instance, this woman spoke to others about the importance of having safe sex in HIV prevention, since this is how she contracted the disease.

Yet, another woman emphasizes staying away from drugs when she talks to others about contracting HIV:

If I was to meet somebody who wants to know how I'm doin' it, share with them the experience that I went through and telling them how I did it. like staying clean, I mean going to prison was one thing that had me like tired. (4)

She also spoke about how she likes to teach others about HIV since she had not learned about it before she was diagnosed with HIV:

And I used to do a lot of speech with kids at school and all that stuff, it helps me a lot... 'Cause I want to teach them what wasn't taught to me. I talk to them about my virus and they ask me questions, how do I take care of myself, what do I do to take my medications, important things. How did I get the virus? So these are important things for me and for them. They ask me how you do it, how you did it, and what are precautions you gotta take and all that stuff, so they learn it...I could give the message that wasn't given to me. (4)

Also, it seems that just helping to make a difference in the lives of others, regardless of relating to HIV or not, can help one cope. One woman copes by being generative and teaching children about life in general:

Talk to kids. Bringing a couple of them kids out and showing them a life that's beautiful. (2)

Positive Coping Strategies

Participants of this study employed a variety of different positive coping strategies in coping with their HIV. Below, positive coping strategies found in the interviews are discussed.

Changing Unhealthy Health Behaviors

Changing unhealthy health behaviors is one way participants cope with their HIV. All four participants made some kind of positive lifestyle change as a means of coping after being

diagnosed with HIV. One participant spoke of how she changed her bad health habits and began to do everything doctors suggest in order to live a healthy lifestyle:

I do practice healthy nutrition, rest, I sleep well... If you rest right, if you eat right, if you take the right vitamins... all of the things that they taught you anyway. If you just do that you got a chance. (1)

This same participant also spoke of how she has stopped doing drugs and even refuses when her siblings ask her to join in. She knows that drugs will not help her in coping with HIV:

My sister and my brother can keep on getting high and I go around them and they always offer it to me but I don't feel that way, "Listen I choose not to get high no more. I really am tired of it y'all". That's what I say... No drugs makes it go away. If you don't get high you don't have no problem with it. (1)

This woman also told of how along with staying away from drugs and alcohol, she is practicing safe sex by not prostituting herself anymore and therefore staying out of jail:

Yep, no more. I have one sexual partner for over 8 years now and I don't use drugs or alcohol or anything illegal no more. I stopped going to prison. I haven't been to jail in over ten years. I was a successful one. (1)

Another woman told of how she has begun to eat properly and to take her medications to prevent her HIV from progressing and to help her cope:

I take my meds faithfully, I eat properly sometimes, I'm a diabetic so I can't really eat too much sweets. I used to until the doctor told me no more, so I've been doin' pretty good.
[Why do you choose these healthy behaviors?]
It makes me feel good. It helps me fight the HIV. (3)

Although she has already stopped drinking, this participant also mentioned that she was trying to quit smoking as well, because she knows it is not good for her health:

And I'm goin' to a smokin' group on Monday to help me deal with it 'cause I tried with the patch and everything I took it off, I couldn't do it. The smokin' group with other smokers smokin' is gonna help me a lot because they're just like me. Gonna help cut down to quit. No drinkin', no drugs. Smoking is, and that's the worst drug. It's hard. (3)

Ceasing IV and other illegal drug use was common among participants, since three of the four participants contracted HIV through IV drug use. One woman reported how she stopped having unprotected sex and stopped using IV drugs:

I stopped sleeping around back then.
 [How did you contract HIV?]
 I got it through the IV.
 [Did that stop?]
 Yes, oh yes. (2)

Another participant also stopped using drugs and alcohol as means of positively coping with her HIV. She also mentions how she keeps herself away from places she knows may cause her to fall back into her old drug use habits that caused her to contract HIV in the first place:

Yep. I stopped using and doing what is right for me and no drugs, no alcohol. You know because being around [my family], I find out that being around my family was a place where I couldn't go because that's where I was raised, Hartford, and if I go there I was gonna end up using – not saying that I will use again, but it's easier for me over there. So I just like I be over here and whenever my boyfriend could bring me to see my mother we go and see her and then come back. (4)

Staying Optimistic

One woman spoke at length about how she practices optimism as a way of coping with her HIV. She was the only one who spoke about this as a coping mechanism. She realized that her anger was controlling her and she decided that she was going to stay positive:

I keep a happy, a jokey- jokey silly-laughey, I'm not very like sit back, mopin' and droopy, you know? I'm not angry anymore because I found out that the way I treat people, if I treat them nice they'll treat me nice so I let go all that anger and fear that I was gonna die because of AIDS. See that what was controllin' me. I was looking at the negative and when I flipped the coin and started doin' all positive to fight this disease, I have not looked back. It doesn't control me. I live life on life's terms. I choose the quality of life that I have. I don't, it doesn't dictate to me what my days gonna be like 'cause when I wake up I push it aside by smiling and saying "Thank you for letting me have another day to live" and then I see people and stuff. (1)

She has decided to take control of her life after contracting HIV by choosing to be optimistic:

But for me, [HIV] ain't gonna hurt me 'cause I choose the quality. Everyday I live like it's my last. Everyday I try to make somebody happy and at the same time make myself happy. And I always think about how blessed and how lucky I am to have a nice apartment, to go from homelessness and drug abuse to not being on drugs for almost five years. (1)

It is her belief that if she stays positive she can keep the HIV at bay. If she can stay positive, she can fight off the HIV:

Yeah I feel happy and good. See times like this how can a negative germ do anything to you when you feelin' so good inside. There's no space for it. It's just out of its element. There ain't nowhere for it to hold on to in here because there's too much joy and happiness. There's not a sad spot or I'm not worried about anything this morning its just happy. [The virus] ain't got anywhere to live when I'm like that. (1)

Another participant simply commented that despite having HIV, she has a positive outlook on her life:

I'm havin' a glorious life, I love life. (3)

Having such a positive view of life despite having contracted HIV may help these women keep their negative emotions subdued. Staying optimistic seems to really help those who discussed it in the interviews, yet only two participants discussed the significance of staying positive.

Fatalistic Mindset/ Blessing in Disguise

An interesting finding was a common fatalistic mindset. Most of the participants reported feeling that contracting HIV was either fate or a blessing in their lives. One woman's initial reaction to her diagnosis reflects her fatalistic mindset:

Well, I was like, "AIDS? That's I mean..." I have heard of it but I felt like if you're gonna die you're gonna die. You know, God's people die for everything, you know. (2)

Another woman views contracting HIV as a blessing from God. Contracting HIV was a chance to change her lifestyle as a drug addict:

He gave me another chance so I gotta thank him and be grateful that I got him in my life. (4)

She went on to describe how contracting HIV was a blessing in her life:

To be honest with you, and I'm not saying this because it's lovely to live with the virus, I think that livin' with the virus has told me and showed me how to live a better life. It might seem like that's bein' sick if I'm thinking like that. But for me, I rather live the life that I'm living life now than the life that I was living before when I was younger. Why I feel like that? It has to do a lot with my past, when I was young, you know all that stuff, you know not that I don't have no worries and not that I don't have no problems but I put limitations, you know, learn how to cope with things and just do whatever I can and leave the rest. (4)

Another woman describes how it is a blessing, an act of fate if you will, that she has survived all of the harm she caused to her body via her drug use. She also goes on to describe how grateful she is to have had such a blessing in life:

All the things I did to destroy my body with drugs. It's a blessing for me to be alive. All them germs I got runnin' around in me and live with malfunctions and I'm still here. Boy my heart, it just pumps like this with great, great, with gratefulness. Grateful, I'm so grateful for life, today, to be able to have made it in spite of the devil and all the thing I've did wrong. I'm fifty something, who'd a ever thought... Humans beings is tough. Check us out. We can adapt to any situation at any time. Like cats. Drop us down on our four feet and we land, and we have nine lives. And no I'm not dead... them nine lives, I've had 'em. (1)

Learning Independence

Learning to become independent was a positive lifestyle change that one participant spoke about during her interview. Making this change in her life seems to have given her a sense of pride:

Yea 'cause I changed how, how like I said like living by myself, like learn how to budget my money and knowing that if I spend my money that money I'm gonna have problems with my rent, with this and that and I gotta be sure I eat properly and I gotta take care of myself, you know. I know the difference 'cause you would have never caught me over here if I was using (drugs) – you know having my own place by myself and everything that I got here is mine. (4)

Going on with Life

Two participants mentioned how their interests or hobbies have helped them in coping with HIV. One woman, who used to be homeless, reports how she no longer lives that lifestyle and has begun to live a healthier lifestyle. It seems she uses her new hobbies to cope in place of the drugs that kept her homeless:

Yes. I just, I don't, I'm not a street person, I like to go shoppin', this television is my everything and I just enjoy life everyday. I try to do the best out of it. (4)

Another participant, after being asked how she copes with being HIV-positive, reported that she relied on her interests to cope with HIV:

I like to sing and listen to music and I like to watch TV, I don't really gotta go out far. Like I say, with kids and talkin' to God, cleanin', decoratin', cooking and watching the TV, the news. (2)

Negative Coping Strategies

Self-destructive Health Habits

One participant admitted that she began to eat more after being diagnosed with HIV. Her eating helps her to deal with the negative emotions she feels:

I eat a lot and just lay around a lot....I eat like a pig. I wish I could control that.
[Why do you think you eat like that?]
I think it's worries, [this disease] stresses me so much, you know. (2)

Although she no longer uses IV drugs, she is also the only participant who has continued to drink and use drugs to cope with her HIV. She also smokes, which seemed to be common among participants:

I smoke, I drink... I still get high every now and then. (2)

Another participant still smokes, but she is trying to quit because she knows it is harmful to her health:

I smoke cigarettes and I need to stop. (3)

Another participant who still smokes but wants to stop comments on how it is harder for her to try to quit smoking than it was giving up drug use:

Smoke yes. That is one thing I am working on. It's hard, it's very hard. 'Cause when you're in this situation, and being by yourself... I want to stop smoking. That's the only behavior that I know not suppose to be doing and I do it. It's just, I feel it's so hard to stop smokin'. Very hard. I thought drugs was hard but this cigarette is more harder. (4)

Depression

While discussing coping strategies, participants were less eager to discuss the use of negative coping strategies in coping with their HIV. One participant recounted of how sometimes she would become so depressed that she would stay in bed and not even get up to use the bathroom:

But let me stay in that bed, boy, it had me. I get to the point where I don't want to go to the bathroom, I don't want to wash myself. I just give up and say, "Why?" just like I say before I had a boyfriend "What's the purpose? Ain't nobody gonna touch me." I wouldn't clean myself until it burned – you know like with baby getting diaper rash and then I'd do it. That was deep depression being like that. (1)

Another participant said that she copes with being HIV positive by withdrawing from the world:

You know, I don't really want to go, I don't want to go to parties I don't go to clubs I don't go to bars, nothing... I just like being at home, cleaning, decorating, cooking, watching TV... I think it's just my distance with the world. So many different, I used to go around here and there everything you know. But now I'm just not for that anymore. Now I just like to be to myself. (2)

Fear

Two participants reported having fear of passing their HIV to their sexual partners. One woman was very open in discussing this fear:

'Cause I don't want to ever think this disease affected his life negatively I don't want to put that... I have a fear of giving it to somebody. I can't even enjoy sex with [her boyfriend] because while we having sex I'm praying for him not to get it this time "Please Lord I'm beggin' for him". Yeah, that's stressful. Sex is stressful for me because, "It's not important enough to give you this germ – Stop!

There's so much more to me. I can entertain a man without you touchin' me. Stop! I don't want the juice, there's a virus in me and if this juice gets on you, ain't no telling where it's gonna go and I don't want to be the one to get you sick" (1)

While she was still an IV drug user, she was careful to warn others of her diagnosis as to not infect someone else:

That's why I always used to tell people when I get high with them with the needles, I'd tell them about the virus. Or to have sex with men, gotta use a condom or I can't do nothin', gotta do this because my lifestyle, you might catch something from me. 'Cause men don't wanna use condoms you know, so I fight it. Because I also think what sin am I committing if I knowing give this germ to someone. What am I doin' destroying they life with they children that's growing up, what am I doing. So I always try to tell God I don't want nobody to get it. So I always in a way find a way to let them know we got to use protection. (1)

Another woman also reported being afraid of passing her HIV onto her sexual partner:

You know when it come to, to, to [sex] it's just hard, it's hard for me 'cause I don't wanna catch no other disease from nobody, I don't wanna pass no disease to nobody. (4)

One participant expressed much fear in relation to various aspects of what may come as her HIV develops. This participant has been living with HIV for over twenty years and one of her fears is that her HIV will develop into AIDS:

Every time I see a bump or swelling or discoloration or rash or a sore throat or a lymph node swelling I automatically think, oh God I'm gonna go from HIV positive to AIDS, full blown AIDS. I don't wanna cross that street yet. I'm still HIV positive but I want to, I'm scared to go to AIDS or the symptoms of it. (1)

She also expressed fear of having to take antiretroviral medication and suffering the consequences she has seen those around her suffer as a result of this medication:

But the side effects they suffer from their medication is not worth the quality of life you get. Who wants to have diarrhea all day everyday. Who wants to have no appetite and watch themselves think, actually get lifeless. Take the medication but can't eat because it burns the inside of their mouth and they get thrush all the time, which is so painful that anytime there's any salt in the food it burns your mouth and – it's ugly. It is ugly what people have to do, some of 'em, to live long with AIDS and stuff. Oh they got stuff that will keep you standin' and walkin',

but your liver swell up, men's stomach gets big like they pregnant, um people change colors. I've seen black girls go from being black, darker to me, to havin', like my girlfriend, burnt pink hair turned baby thin and then burns, something that looks like burns where your hair, just underneath the scalp you can see where it's like a second degree burn. And they lie and say its something else but you know, I know it's a side effect of something they done took. You know, that kind of stuff. Ugly. That's why I'm scared to take medication. I'm not ready. (1)

Although she has many fears surrounding HIV, this participant believes that fear is one way the virus can harm her:

See this disease gets up on fear, it break us down by causin' us to fear this is the end or to give up on yourself 'cause you're gonna die anyway, it tells you. It tells you, well, you know why don't you get high, it talks to you and it's seductive, this disease is and if you don't pay attention to it, it will affect your physical. So the fear intensifies. But it's not the day of end. (1)

Despite all of her fear, she tries to subdue her fears and use more constructive ways of coping with her HIV:

I'm not gonna sit up here – all that stuff I told you is true but it don't come that simple 'cause I be scared a lot. But I get up and I push that motherfucker disease and say you're not controllin' my day today 'cause I'm gonna go get me some love somewhere. Yeah, I'm gonna get it. (1)

Wish-fulfilling fantasy

Only one woman expressed various wish-fulfilling fantasies. Believing these fantasies helps her to cope with her HIV. For instance, one fantasy she has is that if she can only stay positive, the HIV cannot progress and hurt her:

I know I had lived over five years and the next thing I was 10 years and the next thing I was over 15 and now I'm over 20 years. It's like, now I know it can't hurt me. But the disease don't like that. It like stress and it will suck you up if you sad. So many people who have contracted the virus they live the disease. Everyday it's, "Oh my this, my medical, my pills, my kidney, my liver, my" not "Hi! It's a beautiful day" and not even giving the virus the thought of the day. If you push it away it can't hurt you if you fight it. But if you invite it in and everyday you keep talking about it. You know some people live the pain of having HIV and then you have ones like me who are just determined to have a good day. That's all I want. I just want to get through this one day. And you can't hurt me no more because I know what you're trying to do and I can fight you 'cause I learned how to fight

you... You'll notice through your studies that the people who go down quicker and the people who get sick and die sooner are the ones who are constantly at the doctor or constantly in fear. And if you have a positive attitude I don't think it can live in your body. It thrives off of negativity. (1)

She also has a theory that absorbing bleach into her body will kill the HIV in her blood:

Then I had this theory right, I was thinkin' 'cause bleach is the only thing that can kill this, well hypothermia kills it and bleach, so I said okay, so hypothermia's out 'cause I can't heat up my blood and then put it back in so that's too expensive so forget that. But, bleach. So I've been trying to figure out a way to get bleach into my blood system without it harming me b/c that's what kills this. So what I have done, with my little amateur scientific ways, I just, um, I clean up with bleach and I'm not afraid of it, I let it, 'cause I know there are certain ways chemicals absorb in your system, through your skin, inhalation, digestion, absorption, and whatever. I look at all the ways it can get into my system and so I sniff when I'm cleaning with it, I don't take in a lot of it 'cause my mother says it will hurt my lungs. But I'm not afraid to immerse my hands in it for five hours. You understand? I like always use, I'm known when I ask for something from people is to get me a gallon of bleach. 'Cause I'm gonna clean with it and, you know, that's my way I fight it as far as cleanliness. Sanitation – I use bleach and I hope that it's getting' in my system. (1)

It is unknown whether or not the other participants have developed fantasies to help them cope with the reality of their HIV.

DISCUSSION

In this chapter I will first summarize the major findings in light of the previous research. Afterwards, I will describe the limitations and then discuss the implications of this research for future research and interventions.

General Discussion

All participants had come to accept their diagnosis, despite having varying initial reactions. Initial reactions varied from sheer anger and outrage to immediate acceptance. For most of the participants, current feelings about their HIV diagnosis are positive, even for those who had intense initial reactions. Contracting HIV has caused two of the participants to view the disease as an inextricable part of their self-image. As for disclosure, three of the four participants were willing to disclose to both family and non-family. Only one participant had a fear of disclosure to both family and non-family. Two of those that found it easy to disclose attributed this ability as a gift from God.

Only one woman spoke about the complex intersection of old age and HIV. Most of the women interviewed reported that they thought that it would have been more difficult to contract HIV at a younger age. This was a surprising result. It was anticipated that the participants would have thought that contracting HIV at an older age would be harder due to the lack of awareness of older women living with HIV/ AIDS. On the contrary, the participants expressed that they thought contracting HIV at a younger age would be more difficult due to the fact that in the eighties, many people were ignorant about HIV/AIDS and there were a lot of myths surrounding it. Thus, their primary reason for thinking it would be more difficult had to do with the historical aspects of HIV/AIDS, not so much about whether being a certain age when contracting it was better or worse. However, it is also consistent with research in other health areas, such as cancer,

that indicate that persons diagnosed when younger have more difficulty dealing with their disease than those diagnosed when older.

In terms of coping, each participant identified a different aspect of living with HIV as most difficult for coping. Regardless of this finding, participants still employed similar coping strategies. As hypothesized, social support and religious/ spiritual support are important aspects in coping with HIV for all participants. Although all participants lived alone and many of them did not have family around, they all found some form of social support in their community, which they reported has helped in coping with being HIV-positive. At least one of three different forms of social support was available to each participant. The three forms of social support referred available to these women included emotional support, instrumental support, and informational support. Emotional support seemed to be the most valued and sought after source of social support.

Social Support

From the information gathered from the interviews, it seems that the use of social support as a coping mechanism for these women provides positive consequences. This is similar to what the previous coping literature suggests. Turner-Cobb and colleagues (2002) stated that social support is associated with less mood disturbance, which seemed to be true for participants of this study. Not only did participants of this study express the emotional and instrumental benefits provided by the social support in their lives, but the opposite was reported as well. Some participants spoke of the negative effects and emotional distress caused by not having social supports accessible. This was especially true in terms of family. Reports from these participants also support the claims made by researchers Shippy and Karpiak (2005) and Heckman and colleagues (2001) that many older individuals with HIV/ AIDS do not possess adequate means of

social support. Although all of the women had some form of social support available to them, all participants lived alone and the sources of social support that were available were limited. Most of the participants had just a few sources of social support to rely on from their families, if they could access their families for support at all. It is uncertain whether or not these women had more resources of social support before their diagnosis, as the research of Turner-Cobb and colleagues (2002) suggests. Many of the participants interviewed in this study were IV drug users and had been homeless prior to contracting HIV; it is possible that lifestyle may have isolated them from many sources of social support prior to contracting HIV.

It also seemed to be accurate that social support is a mediator of emotional distress caused by stigma and rejection by family members of individuals living with HIV, as hypothesized by Heckman and colleagues (2004). One participant spoke of how she did not have the support of her family, and the pain that caused her. She was the only participant who reported that social support from her family “works against” her, since they have distanced themselves from her. Yet, the social support she receives from the kids in her community helps mediate the negative emotions felt from the rejection of her family.

Religious/Spiritual Support

Religious/ spiritual support was also a constant theme among participants. This, too, is reflective of other HIV/ AIDS coping literature. Three different aspects of social support aided these women in coping with their HIV. Praying to God was commonly practiced among all participants of this study, which supports previous findings that prayer is an important and common form of coping among women with HIV (Biggar et al., 1999; Simoni & Ng, 2000). Having faith in God was also commonly practiced among participants. Likewise, having the

belief that God has the ability to aid one in coping with HIV as well as the power to offer protection helped most of the women to cope with their HIV.

For women in this study, using religion/ spirituality to cope with their HIV had similar effects to Siegel and Schrimshaw's study (2002) on HIV-positive African American women over 50 and the role of religion as coping in their struggle with HIV/ AIDS. It seems that participants in this study gained many of the same benefits from the use of religious coping as did their participants. It appears that participants of this study gained emotional support, feelings of control and empowerment, a diminished emotional burden as a result of the HIV, and the ability to reinterpret the meaning of the illness, just as the aforementioned study has shown.

An interesting outcome was the intersection of social support and religious support. It seems that a big part of social support involves religious support as well, as many of the women relied on their social supports to help cultivate their faith in God. It seemed that the social supports of some of these women were important sources of support because they helped to encourage the use of religious support. Similarly, using religion to cope is a form of social support. Praying to God gives these participants someone who is available all the time, someone to talk to throughout the day, and someone to look after them.

Education

One outcome the researcher was not anticipating on the basis of previous research was the use of education to cope. Education was a constant theme, whether it was educating oneself about the disease to better understand it or educating others as to prevent them from contracting HIV. There was no interview question that asked about education, yet it was discussed in every interview. It is possible that the lack of education of these women, including lack of education about HIV/ AIDS, may be why educating themselves was so important for coping. Only one

woman had some college education while the other three did not even graduate high school. All participants knew little about HIV/ AIDS at time of diagnosis. The use of education was a surprising finding that was not addressed in the previous HIV/ AIDS coping literature. Use of the Internet as a mode of self-education was discussed by only one participant. It seemed to aid in her coping because it aided in her need to educate herself about HIV. Yet, her use may reflect what Kalichman and colleagues (2006) indicated, that people facing life threatening and debilitating illnesses, such as HIV/ AIDS, may be particularly vulnerable to misinformation on the Internet. This woman used the Internet to seek out information about ways to “cure” her HIV, which fed into her wish-fulfilling fantasies.

Specific Positive and Negative Coping Strategies

A variety of different positive coping strategies were employed by the participants in coping with their HIV. All four participants made some sort of improvement in some unhealthy health behavior since their diagnosis, such as eating poorly or using alcohol and drugs, but only one participant reported to be completely free of negative health behaviors. Staying optimistic was also a coping strategy used by two of the participants. Also, the majority of participants either had a fatalistic mindset towards having contracted HIV, meaning they believe it was fate, or they believe that contracting HIV was a blessing in their lives. Other positive coping strategies included improving general quality of life by either gaining independence or by using interests and hobbies to cope with the stressors of having HIV.

All participants engaged in negative coping strategies at some point, although these seemed to be discussed less throughout the interviews. This may be due to the finding that few women with HIV/ AIDS acknowledge negative coping mechanisms (Simoni & Ng, 2000) or that they weren't asked about directly enough. Participants did not speak of having negative physical

symptoms associated with more advanced HIV or AIDS, most likely because none of the participants were in advanced stages of HIV. Three of the participants reported still consciously engaging in some form of destructive health behavior. Two of the participants smoke, yet are trying to stop, while the third continues to do drugs and drink occasionally, with no apparent desire to curtail or cease this behavior. Negative emotions of depression and fear were present as well. Only two participants mentioned feelings of depression. Similarly, not many participants reported feeling fear. Two expressed fear in passing their HIV to others. Only one expressed explicit fear in what may come with being HIV-positive. Wish-fulfilling fantasy, a coping mechanism employed by individuals with HIV according to the coping literature (Commerford et al., 1994), was another negative coping mechanism discussed. Yet, it was only employed by one of the participants. There is a possibility that this is used more commonly among HIV-positive women over 50 than this sample suggests.

Research conducted by Ashton and colleagues (2005) concluded that a greater rate of progression of HIV is correlated with individuals who use maladaptive or negative coping strategies, yet no conclusive correlations can be drawn from this finding to the results of this study. In this study, only the information regarding the HIV status of participants was gathered by the participants themselves. On the other hand, the one participant who had not given up many of her negative coping strategies, including the use of drugs and alcohol, also reported hearing from her doctor that her HIV was progressing.

Coping literature on negative coping strategies suggests that self-blaming denial, wish-fulfilling fantasy, and emotional expression were associated with a lack of acceptance of HIV/AIDS, avoidance, and a general negative affect (Commerford et al., 1994). This study does not support this finding, considering all participants have reportedly accepted their diagnosis despite

any negative emotions or coping strategies they employ. Commerford and colleagues (1994) also found a positive correlation between wish-fulfilling fantasy and negative affect, which also was not a result of this study. The one participant who exhibited wish-fulfilling fantasies surrounding her HIV also had the most optimistic mindset surrounding being HIV-positive compared to any of the other participants.

Limitations

This study had many limitations that can be improved on in future research. This study employed a semi-structured set of questions, which should be expanded upon in future research as well. Questions should be based on, and expand on, research that has already been conducted and suggestions for future research given by other researchers in the field.

Another limitation is the small sample size of four participants. A larger sample size will help to generalize future results to the greater population of women over fifty with HIV/ AIDS. Similarly, having a less homogeneous group of participants would improve on future research, since most of the women in the study were African American, had little formal education, were from one metropolitan area, and were all between the ages of 50 and 60. Also, importantly, although all were HIV+, none of the respondents reported being diagnosed with AIDS. A more diverse sample size in terms of race/ethnicity and age would better demonstrate the needs of this population and the possible differences and similarities in coping between various ethnic groups of women over 50 with HIV/ AIDS and between women in their 50s and women in their 60s or 70s. Also, recruiting participants with different educational backgrounds may change needs for certain coping strategies over others. And, of course, women with full AIDS may have reacted differently to their situation than those who are HIV+ but have not progressed to AIDS. This is partly confirmed by the reactions of the one woman who did report some progression in her

disease. In general, a more diverse group would provide a good base of research for understanding this “invisible” group of women. Yet, despite the limitations, this study provides an important window into the lives and coping strategies of older women with HIV.

Implications and Future Research

Findings from this study have many implications for future research. Since older women living with HIV/ AIDS have been largely overlooked by physicians and policy makers, much more research needs to be conducted on this population. Yet, results from this study help to point out some specific areas that should be given specific attention.

Since social support provides an important source of coping for older women living with HIV, future research should focus specifically on further understanding these sources of coping so that policy makers could create more effective ways for older women to better access these sources of support. This holds especially true for helping older women with HIV to increase their social support networks. Effective interventions and programs based on solid research should aim to increasing women’s abilities to utilize sources of support and increase their own social support networks.

Furthermore, future researchers may want to inquire more about the HIV-related loss and bereavement that HIV-positive individuals face when they lose loved ones to AIDS. This was not discussed among participants in this study, but it appears in the coping literature. Further investigation is needed on this topic, since loss and bereavement related to HIV/AIDS could have a significant impact on an individual’s experience coping with HIV/AIDS and could contribute to decreased social supports.

Religious/ spiritual support, as well, is clearly an important source of support for older women living with HIV. Future research should focus on identifying what types of interventions

would help women to utilize this support more and provide religious social networks that could double as both forms of support.

The previous implications are similar to what was found in other studies and, thus, are verifications of what others have said. However, one area that complements other research and is an innovative finding is the importance of education. Education seemed to be of great importance to these women coping with HIV. Results show that education is important for older women with HIV, and thus more educational services and programs should be geared towards educating older women about HIV and how to cope with it, along with allowing HIV-infected older women to be active in peer education. Older women are also often excluded from HIV-related education and prevention programs (Emlet & Farkas, 2001), so it would be useful to create such programs for this population of women. It would also be worthwhile to see if more older women with HIV use Internet as a self-education tool, and, if so, how this contributes to coping with HIV. Does the Internet provide useful information to most participants, or does it provide more misinformation that complicates coping?

Future research should expand on the range of participants to add even more depth to these findings. Areas of exploration should certainly include the role of religion/spirituality, the specific nature of social supports, and the use of education. Also, understanding what prompts older women with HIV into positive health behavior changes is not only relevant for research, but also for interventions that enable those fighting the disease to follow behaviors that make them healthier in general, as well as specifically better able to control their HIV/AIDS progression. Future researchers should also specifically ask about the various negative coping strategies, as it seems many older women are more inclined to deny these or not mention them.

Including coping skills training into educational programs for older women with HIV may also help to increase the use of positive coping strategies and reduce negative strategies.

Another specific area of inquiry should be the complexity of aging and living with HIV. As one participant pointed out during her interview (Participant 1, p. 33), researchers should ask specific questions about this intersection. Asking these questions would also be useful in planning interventions and organizing sources of instrumental support for older women with HIV.

The comments of these four women clearly illustrate the struggles and difficulties associated with HIV/AIDS and its repercussions on many aspects of life, such as social support. They also show the contexts of difficult lives even pre-diagnosis, which form the background for how they deal with HIV status. These include the IV drug use that resulted in infection for most, prison, and other negative aspects. Yet, the results also show the resilience of these women's lives in the ways they are living fully with HIV rather than dying from it. Indeed, most report positive benefits in terms of relationships with God, connections with others, a sense of self as capable, and, for most, at least some changes in health behavior, including giving up what initially led them to this place in their lives.

APPENDIX 1

Interview Guide

I. First, I want to ask you some questions about yourself.

Question 1. Tell me about yourself. For example...

- a. How old are you?
- b. How long did you go to school for?
- c. What do you do for a living?
- d. Are you married or in a committed partnership; if so, how long have you been married or in this partnership?
- e. Do you have any children; if so, how old are they?

Question 2. Would you call yourself religious or spiritual? If so why? What religion do you practice or what belief system do you follow? For example, would you consider yourself to be Christian, Jewish, Buddhist, etc?

Question 3. How would you describe your living arrangement right now? In other words, who do you live with? Why is this the case? Or do you live alone? If so, is this your choice? Why or why not?

II. Now, I would like to ask you some questions about living with HIV or AIDS.

Question 4. When did you find out that you were HIV-positive? How (under what circumstances) did you find out this information?

Question 5a. What were your initial feelings or reactions to being HIV-positive?

Question 5b. What are your feelings now? In other words, are your feelings the same now as they were back when you first found out that you had HIV? Why or why not?

Question 6. If you experienced any negative types of emotions when you first found out that you have HIV, how do you think that you've resolved some of these feelings? In other words, what have you done to try to reduce the negative feelings of knowing that you have HIV?

Question 7. Have you accepted your diagnosis? When did you accept it? How (under what circumstances) did you realize that you accepted your diagnosis? Or, if you have not accepted the diagnosis of having HIV (or AIDS), what do you think keeps you from accepting it?

Question 8. Have you been diagnosed with AIDS? Do you believe that you show any signs or symptoms of AIDS? Why or why not?

Question 9. Have you told anyone about your diagnosis (of either HIV or AIDS or both)? If so, who have you told and who have you not told? Why did you choose to tell the people you told and choose not to tell others. If not, what are your reasons for not wanting to tell this information to others?

Question 10. How has your lifestyle been affected by having HIV (AIDS)? In other words, what sorts of changes have you made after learning that you have HIV (AIDS)?

Question 11. In most people's minds, contracting HIV happens in young adulthood. Do you think your experience with HIV/ AIDS would be different if you had contracted it at a younger age?

III. Now I would like to ask you a few questions about how you've dealt with being HIV-positive.

Question 11a. Since the time that you learned you were positive for HIV (AIDS), what have you found to be the hardest aspects of being HIV-positive (or having AIDS)? Why?

Question 11b. How do you deal with being HIV-positive (or having AIDS)? For instance, do you engage in behaviors (e.g., antiretroviral medications/protease inhibitors, exercise, visits to a health care provider) that help you to stay healthy? If so, which ones? Why have you chosen these behaviors over others?

Question 12. Are there any behaviors (e.g. smoking, alcohol use, IV or other forms of drug use) that you engage in that you think might harm you or hurt your health? Please explain.

Question 13a. In what ways would you say that the social support of family, friends, and others has helped you to cope with being HIV-positive (or having AIDS)?

Question 13b. Are there ways that the social support of family, friends, and others has 'worked against' you, so to speak, and not helped you and your situation? Please explain.

Question 14a. In what ways would you say that religious or spiritual beliefs have helped you to cope with being HIV-positive (or having AIDS)?

Question 14b. In what ways would you say that religious or spiritual beliefs have 'worked against' you, so to speak, and not helped you and your situation? Please explain.

Question 15. We have talked about the ways in which social supports and religion or spirituality can help or hinder someone living with HIV/AIDS.

- a. What are some other ideas/things/ways that you think can help you or someone else in dealing with HIV (or AIDS)?
- b. What are some other ideas/things/ways that you think will not help you or someone else in dealing with HIV (or AIDS)?

Question 16. Is there anything else that you would like to say about what it is like to live with HIV (or AIDS)? Please feel free to share anything that you want to share.

Thank you very much for taking the time to talk with me.

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